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Perspectives of Patients in Identifying their Values-Based Health Priorities

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Abstract

Objectives: Patient Health Priorities Identification (PHPI) is a values-based process in which trained facilitators assist older adults with multiple chronic conditions identify their health priorities. The purpose of this study was to evaluate patients' perceptions of PHPI.

Design: Qualitative study employing thematic analysis.

Setting: In-depth semi-structured telephone and in-person interviews.

Participants: Twenty-two older adults who participated in the PHPI process.

Measurements: Open-ended questions about patient perceptions of the PHPI process, perceived benefits of the process, enablers and barriers to PHPI, and recommendations for process enhancement.

Results: Patient interviews ranged from 9–63 minutes (median = 20 minutes; Interquartile range = 16.5). The mean age was 80 (standard deviation = 7.96), 64% were female, and all patients identified themselves as white. Of the sample, 73% reported no caregiver involvement in their healthcare and 36% lived alone. Most patients felt able to complete the PHPI process with ease. Perceived benefits included increased knowledge and insight into disease processes and treatment options, patient activation, and enhanced communication with family and clinicians. Patients

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identified several factors that were both enablers and barriers to PHPI including facilitator characteristics, patient demographic and clinical characteristics, social support, relationships between the patient and their primary care provider, and the changing health priorities of the patient. Recommendations for process enhancement included more frequent and flexible facilitator contacts, selection of patients for participation based on specific patient characteristics, clarification of process aims and expectations, involvement of family, written reminders of established health priorities, short duration between facilitation and primary care provider follow-up, and the inclusion of health-related tasks in facilitation visits.

Conclusions: Patients found the PHPI process valuable in identifying actionable health priorities and healthcare goals leading to enhanced knowledge, activation, and communication regarding their treatment options and preferences. PHPI may be useful for aligning the healthcare patients receive with their values-based priorities.

Keywords

Patient Priorities; Preferences; Goals and Goal-Setting; Older Adults; Multimorbidity

INTRODUCTION

Older adults with multiple chronic conditions and their caregivers, frequently report that their medical regimens are as burdensome as the conditions they are intended to treat.¹⁻⁴ Patients with multiple chronic conditions often see several primary care and specialist providers per year, have complex medication regimens involving multiple medications, and complete self-monitoring tasks on a daily basis.^{1,5} These patients also vary in their health priorities. Health priorities are the health outcome goals patients most desire from their healthcare within the context of their healthcare preferences, that is the healthcare activities that patients are willing and able to do to achieve these outcomes.⁶⁻¹² Healthcare decision-making informed by patient health priorities allows clinicians to align their plan of care to what matters most to the patient, avoiding conflicting recommendations, better selecting among various care options, and reducing treatment burden.¹¹

In 2014, a national group of stakeholders representing varied healthcare perspectives (clinicians – both primary and specialty, health system leaders, health insurance providers, patients, caregivers, experts in health IT and design) initiated an 18 month process to design a healthcare prototype to help patients with multiple chronic conditions identify and communicate their health priorities.¹³ In this patient-centered approach, a facilitator (who is a member of the healthcare team) helps patients identify their health outcome goals and healthcare preferences (i.e. patient health priorities) and transmits this information through the electronic health record to the patients' clinicians. During a follow-up visit, patients, caregivers, and clinicians then collaboratively make healthcare decisions that align with these patient health priorities. This values-based decisional process is referred to as Patient Priorities Care (PPC).^{13,14}

We previously described the development, refinement, and implementation of PPC and of the Patient Health Priorities Identification (PHPI) process component, the first step in PPC, elsewhere.¹³⁻¹⁵ We then sought to solicit patient perspectives of the PHPI to iteratively

improve the process for future work and applications. Therefore, the purpose of this qualitative study was to describe patients' perceptions of the PHPI process, identify enabling factors and barriers to the process, and elicit recommendations from patients on process enhancement.

METHODS

Study Design

Methods and results are reported in accordance with the Consolidated Criteria for Reporting Qualitative Research.¹⁶ The PPC program was developed and piloted in a primary care practice located in Connecticut.^{13,15} The PPC pilot involved ten primary care clinicians and five cardiologists who provided cardiology care, if needed to patients from the primary care practice. Two PPC health priorities facilitators (an advanced practice nurse and a case manager), both members of the primary care practice team, conducted the PHPI sessions. Facilitator training has been described elsewhere.^{13,15}

Patient inclusion criteria for participation in PPC included having three or more chronic conditions, prescribed at least 10 medications, seen by >2 specialists over the past year and English-speaking. Exclusion criteria included advanced dementia, chronic dialysis, residing in a nursing home, or meeting hospice eligibility. The final decision regarding patient participation in PPC was left to the patient's primary care clinician. The patient's primary care clinician invited the patient to participate in the intervention during a clinic visit. Following consent, facilitators completed the facilitation session with the patient, either in the clinic after the primary care visit, at the patient's home, or by telephone. Facilitators collected baseline patient data, including patient demographics and clinical characteristics, at the time of the facilitation visit and from the patient's electronic health record. The PHPI component of PPC followed a scripted process to assist patients in identifying health priorities.^{13,15} The result of the patient-facilitator process was a template that described what mattered most to the patient including their specific, reliable, and actionable health outcome goals and healthcare preferences, as well as their self-perceived health trajectory.¹⁵ Upon completion, the template was uploaded to the electronic health record to inform subsequent healthcare recommendations and decision-making.^{15,19} Patients received a second telephone call or visit from the facilitator one to two weeks after the initial visit. During this call or visit, the facilitator assisted patients to refine their health priorities and prepared them to communicate their health priorities with their clinician. The study was approved by the Yale University and Baylor College of Medicine Institutional Review Boards.

Sample

All eligible patients who completed at least one PHPI facilitation session between 10/2016 – 9/2017 (n=48) were mailed letters inviting them to participate in a semi-structured, qualitative interview. Patients were contacted by telephone 1–2 weeks after the letters were mailed to obtain consent and schedule an interview. Patients were offered a \$25.00 gift card as reimbursement for their time participating in the interview.

Procedures

The patient's verbal consent was obtained prior to data collection. Qualitative interviews took place over the telephone or at a location of the patient's choosing. An experienced interviewer (SLF) conducted all interviews, which were digitally recorded and professionally transcribed and redacted. All interviews followed a structured interview guide. Specifically, patients were asked about their overall thoughts of PHPI, perceived benefits, enabling factors and barriers, and ways to improve the PHPI process.

Data Analysis

The inductive qualitative approach of thematic analysis¹⁷ was used to analyze interview data, an approach that relies on the synthesis of qualitative data to identify patterns and develop themes across experiences. The coding team was comprised of SLF, a doctorally prepared nurse practitioner with qualitative expertise and EK, a masters-level research associate. Atlas.ti qualitative software (Scientific Software, Berlin, Germany, version 5.0) was used to manage and analyze study data.

The coding team began with a line-by-line review of transcripts and open coding of data using descriptive phrases to identify key concepts. Following review of the first five transcripts, coders developed an initial code key, which was reviewed with the full study team. This code key was expanded and refined through independent and then joint review of subsequent transcripts. Coders compared codes until achieving agreement on all codes, code meanings, and conceptual categories. Coding discrepancies were adjudicated via group consensus. Coders then applied the final code key to all transcripts, produced code reports, and analyzed reports to develop themes. Coders created memos to capture thoughts and questions about the data during this analytic process. Recruitment, interviewing, and coding occurred concurrently until data saturation was reached.¹⁸ Coders shared findings with the full study team for feedback throughout coding and analysis.

RESULTS

Of the 47 patients who were sent letters, 32 were reached by telephone; 22 patients (69%) consented and completed interviews. There were two in-person and 20 telephone interviews. Interviews ranged in time from 9 to 63 minutes with a median of 20 minutes (Interquartile range = 16.5). Patients' mean age was 80 (SD 7.96) years; 64% were female; all patients identified as white (Table 1). Thirty-six percent of patients had some college education or higher; 5 (23%) were Medicare/Medicaid dual eligible. Of the sample, 73% reported no caregiver involvement in their healthcare and 36% lived alone. Mean number of comorbidities per patient was 5.3 (SD1.94).

Perceptions of Patient Health Priorities Identification

Patients reported that the PHPI process gave them the opportunity to discuss and "sit down and really think (P184)" about their health and health priorities in an expanded, proactive way. Patients viewed the content and context of the PHPI, and their conversations with facilitators, as distinct compared to conversations with other clinicians. Patients described facilitation sessions as more personal, detailed, and more involved than typical encounters

with healthcare providers. “You go to the other doctors and they don’t really take the time to do this,” a patient said, “to find out what they could do to make things more beneficial to older people (P5).” Patients endorsed the purpose and intended outcomes of the PHPI process reporting that they were able to identify actionable goals and make specific changes “about what I wanted and what issues I had (P184).” Most patients felt they were able to identify their health priorities with relative ease.

Several patients offered constructive feedback on the PHPI process. Patients felt that the purpose of the PHPI process could be clarified and differentiated from other home healthcare encounters, such as in-home annual physical examinations. Some patients found the facilitator’s questions regarding health outcome goals and what mattered most to the patient difficult to answer. Patients identified several reasons for this, including an unclear understanding of what was being asked, limited exposure to discussing such topics during past healthcare encounters, or because the questions required a significant amount of thought and reflection on the part of the patient. “I had to think to answer them (P9),” a patient reported.

Perceived Benefits of Patient Health Priorities Identification

Patients identified several benefits of the PHPI process (Table 2.) Patients reported gaining in-depth knowledge of their health during the facilitation visit and a better understanding of the healthcare tasks they could undertake to help improve their quality of life. In some cases, the PHPI process aided patients in acknowledging limits on attaining their goals and preferences in the context of their current functioning or life circumstances. Patients described feeling activated to take responsibility for their healthcare and noted increased confidence in maintaining their health as result of participation in the PHPI.

Patients found that participation in the PHPI process led to changes in the ways they communicated with their family as well as other clinicians. Patients described being able to speak with family “more freely (P142)” after the facilitation and viewed the facilitation as a catalyst for talking to their family about their healthcare goals and preferences. Patients also reported feeling empowered to ask questions of clinicians as the result of the PHPI process, for example, in seeking clarification of the purpose and consequences of medical treatments or the likely impact of such treatments on quality of life.

Enabling Factors and Barriers to Patient Health Priorities Identification

Patients identified several enabling factors and barriers to PHPI. In most cases, these factors were both an enabling factor and barrier to participation in the PHPI process. Factors included facilitator characteristics, patient characteristics and support, the relationship between the patient and their clinician, and the changing priorities of the patient (Table 3).

Facilitator characteristics that could enable or act as a barrier to the PHPI process included the facilitator’s personality, communication style, and knowledge, comfort, and training with the PHPI process. Patient characteristics including demographic factors (e.g. age, income), and clinical factors (e.g. past and current medical conditions), and external life circumstances such as caring for adult child, could also help or hinder patients’ ability to participate in PHPI. “The goals... we cannot do them right now because we are caretakers

for my son. So we're kind of stuck at home" a patient and his wife reported (P152). Patients reported that social support (e.g. caregivers, adult children, friends) helped the patient to both identify and communicate their health priorities during the PHPI process. Conversely, patients felt that a lack of such supports could make identification of health priorities difficult.

Patients reported that they were more likely to participate in the process when their clinicians were enthusiastic and encouraging of PHPI. Others stated they would likely not have participated had their clinicians been indifferent or non-supportive of PHPI. Patients felt their health status at the time of PHPI (e.g. whether they were in excellent or poor health) influenced their perceptions of the utility of the process. For example, patients who reported themselves to be in good health believed that patients in poorer health or patients with more complex medical needs and regimens would derive the most benefit from the PHPI process.

Recommendations for Enhancing the Patient Health Priorities Identification Process

Patients provided several recommendations for enhancing the PHPI process (Table 4; Supplementary Table S1). Several patients desired more frequent and flexible contacts with the facilitator. For example, patients requested sessions that could be delivered in the home or over the phone and could be tailored to their individual needs and characteristics such as in cases of a patient's recent illness or hospitalization. Others suggested targeting the PHPI for specific patient populations, such as patients in poor health with shortened prognosis or with limited social support.

Patients suggested clarification of study materials to underscore the core purpose of the process. To facilitate recollections of what was discussed during the facilitation visit, patients suggested that clinician follow-up visits be scheduled within 1–2 weeks of the first facilitator visit. Patients also recommended that they be provided with documentation of their health priorities such as take-home reminders or a summary that they could bring with them to follow-up appointments.

Patients desired a reduction in the number of forms they were asked to complete as part of the PHPI process. In addition, patients emphasized that it was important to include caregivers, family members, and other social support in PHPI discussions and recommended that these individuals be formally involved in PHPI sessions. Several patients also suggested broadening the scope of the intervention to align it with a more typical clinician visit (e.g. review of health problems, discussion of medications) and include health monitoring tasks, (e.g. measurement of blood pressure, collection blood for lab work).

DISCUSSION

Older adults with multiple chronic conditions are often faced with complicated and time-consuming healthcare regimens that may not always align with their individual healthcare goals and preferences. This study evaluated patients' perceptions of the PHPI process, a process that enables patients to identify their health priorities. That is, the health outcome goals they most desire and the tradeoffs they are willing and able to do to achieve such

outcomes. Patients found the PHPI process enjoyable, with most reporting ease in the identification and selection of health priorities. Results from this study demonstrate that patients can successfully participate in the PHPI process and that participation in PHPI is perceived to result in benefits for the patient as well as the patient-provider relationship.

Several patients suggested that facilitators conduct the PHPI facilitation session similar to that of a typical clinician encounter, with the identification of health problems, discussion of medications, and the completion of health-related clinical tasks. However, the intended purpose of the PHPI facilitation visit is to identify the patient's desired health outcome goals and preferences, rather than focusing on the means to achieving them. The PHPI facilitation provides clinicians with the patient's health priorities, which allows them to identify and align the best care options to accomplish these priorities at their follow-up appointment. This sequential approach allows ample time for the patient to discuss their health priorities with the facilitator, while keeping the facilitator visit to a reasonable time interval.

Patients viewed caregivers, family members, and other social support as having an important role in the success of the PHPI process. Patients felt these individuals should be involved in PHPI that they should be encouraged to voice their opinions on patient-identified health priorities, and conversely, felt that a lack of such support often made identification of health priorities difficult. These data suggest that patients may view their health priorities as influenced by the views, and potentially the health priorities, of their caregivers and others. This finding aligns with past reports of factors that influence care preferences among older adults²⁰ and underscore the importance of caregiver participation in the PHPI. Avenues for additional research may involve the use of a patient-caregiver dyadic approach to healthcare goals and priorities facilitation.

Other interventions have focused on identifying patient priorities for patients with multiple chronic conditions, though these interventions have primarily been intended for patients with advanced illness or near the end of life.²¹⁻²³ Notably our study findings are similar to these past reports²¹⁻²³ as patients in our study also found these conversations as helpful, activating, and patient-centered. What makes the PHPI process unique is it promotes identification of priorities that relate to the whole person, encompassing the interactions among multiple conditions rather than a focus on a single serious or advanced illness.

Encouraging patient involvement in conversations during routine clinical encounters about the trade-offs among outcome goals, care preferences, and care options, can normalize early and frequent discussion of patient priorities. Earlier conversations about patient priorities may make similar conversations at crucial transition points, such as in advanced illness or at the end of life, less difficult. Through participation in the PHPI, patients can develop "current care" plans that align and will continue to align with their desires and abilities, even as their disease progresses. Additional research is needed to determine the ideal timing and frequency of such conversations, as well as the association between these conversations and changes in patient priorities and outcomes.

There are several limitations to this study. There is the potential for selection bias given that the qualitative study was sampled from a restricted geographic area and was limited in terms

of racial diversity. Results from the current study may not apply to other populations such as nursing home residents or patients with other racial or ethnic backgrounds. The median interview length was 20 minutes, a duration which could have limited the granularity of study findings. However, our structured interview guide included probes to facilitate participant recollection of the PHPI process, interview length was determined by patient preferences, and interviewing and coding occurred concurrently until data saturation was reached.

Implications and Next Steps

Findings from this study, as well as the feedback obtained from PHPI facilitators¹⁵, has led to several iterative revisions of the PHPI process. In order to clarify the content and context of the PHPI, we revised the facilitator guide and patient materials to clarify the questions asked by the facilitator, explanations provided by the facilitator, and key PHPI concepts discussed during the facilitation session. Patients were given copies of their priorities template and a conversation starter document to take with them to their follow-up clinician visit in order to reinforce what was discussed during the facilitation session. Based on input from patients and clinicians¹⁵, we added the “specific ask” to the PHPI, the one thing that the patient most wants to focus on in their health or healthcare to achieve their most desired activity more often or with greater ease. We also shortened the time interval between PHPI and the following clinician visit and added the option of meeting with the facilitator during the same visit in which the clinician invited the patient to participate in PPC.

Our ongoing work includes obtaining clinicians’ perspectives of PPC and assessing PPC’s effect on aligning clinical decision-making and care with patient priorities and on patient and clinician outcomes. We will disseminate the PHPI process and PPC following completion of this evaluation. In the meantime, patients viewed the PHPI process as feasible and effective in assisting them to identify their health priorities, engaging them in their care, and potentially aligning the healthcare they receive with the priorities they value most.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Definitions:

- Health outcome goals are the health and life outcomes that patients' desire from their healthcare.
- Healthcare preferences refer to the healthcare activities (e.g. medications, self-management tasks, healthcare visits, diagnostic testing, and procedures) that patients are willing and able to do or not willing or able to do.
- Patient's health priorities are patients' specific health outcome goals that they most desire from their healthcare within the context of their healthcare preferences.

Table 1.

Sample Characteristics

Variable	N = 22
Age, m (SD)	80 (7.96)
Sex, n (%)	
Male	8 (36)
Female	14 (64)
Race, n (%)	
White	22 (100)
Ethnicity, n (%)	
Non-Hispanic or Latino	17 (77)
Did not answer	5 (23)
Education level, n (%)	
Less than high school	1 (4)
High school/GED	5 (23)
Some college	5 (23)
Bachelor's degree	2 (9)
Graduate or post-graduate degree	1 (4)
Did not answer	8 (36)
Insurance, n (%)	
Medicare	10 (45)
Medicare Advantage	7 (32)
Medicare/Medicaid	5 (23)
Caregiver involved in healthcare, n (%)	
Yes	6 (27)
No	18 (73)
Lives alone	
Yes	8 (36)
No	14 (64)
Number of chronic conditions, m (SD)	5.3 (1.94)

Table 2.

Perceived benefits of Patient Health Priorities Identification process

Benefit	Exemplar Quotes
Knowledge or insight into patients' health and healthcare	
Learning to ask questions	"It's somebody who could help me to find out how to get help for something, to listen." (P5)
Gaining knowledge of care options	"The [PHP] process just didn't seem as perfunctory as when you go do the doctor. [The facilitator] wanted to know more in detail how does that affect you and what would you like to change." (P161)
Reinforcement of the patient-clinician relationship	"Well, it got me to realize that the doctor's office and my own doctor are truly interested in my health." (P182)
Patient activation	
New perspectives of health and healthcare, goals, and objectives	"I found it interesting. It was helpful. It helped me sit down and really think about things, versus just kind of reacting day-to-day. It helped me refocus my thoughts and really kind of verbalize my priorities." (P184)
Assertiveness and confidence	"Cuz it's changed my assertiveness, where I used to keep it to myself. I think it's given me more confidence in living alone at my age." (P142)
Motivation for change	"She suggested maybe a nutritionist to talk to about the weight and stuff like that, which I've been going to. I needed the push, I guess, to ask to go see one." (P9)
Communication	
With family	"To be more open with my girls, because they're really holding my life in their hands, because they do know that I have a living will. And I do want it respected." (P142)
With clinicians	"Well it's taught me to speak up, because I'm the type of person that, you know, "Oh, well, it's minor, I won't mention it." (P161)

Table 3.

Enabling factors and barriers to the Patient Health Priorities Identification process

	Enabling Factors	Barriers
Facilitator characteristics	<p>"[Facilitator] is easy to talk to, and she knows the different questions to ask to get around and into things. And, she made it a lot easier." (P9)</p>	<p>I thought it was gonna be a similar type of a situation [as a different home visit] where they were gonna come out and really evaluate my health. But it was—it was just basic—some basic questions. It was—actually, it was very quick." (P146)</p>
Patient demographic and clinical characteristics	<p>"Well, they put me on several other medications when I'd had the stroke, and I'm on so many, I don't know what the heck they're for. So she [facilitator] could explain to me what they were for. That helped a lot, because I just know I'm taking a lot of medication. I don't like taking all these pills." (P9)</p>	<p>"I pushed back a lot of doctors because I was on overload. I couldn't cope with it all" (P5).</p>
Patient social support (e.g. caregiver, spouse)	<p>"I keep my husband around 'cuz he tells me these things, because I can't think of 'em" (P5).</p>	<p>"I don't really get into conversations about my health with my family that much. They live miles away from me." (P124)</p>
Relationship between the patient and their primary care provider	<p>"He [clinician] said it's very important to him to find the questions that you might have that you didn't ask me or a treatment that you think might have helped. In other words, help him [help me] with my problem." (P142)</p>	<p>"Some of 'em are very not receptive. Sometimes you have no choice but to stick with that doctor. So basically when that happens, you just don't raise the issue. Which is not the way the doctor-patient relationship should be." (P197)</p>
Changing priorities of the patient	<p>"But I think it's important to check like twice a year to see the changes that have happened. Because we are changing day by day." (P35).</p>	<p>"I don't feel that I'm really qualified for this because my health is in excellent condition...I didn't have that many issues so I didn't feel I was a very good candidate" (P182).</p>

Table 4.

Patient recommendations for the Patient Health Priorities Identification process

Theme	Recommendation Specifics
More frequent home visits	<ul style="list-style-type: none"> • Monthly to bi-monthly in-home facilitator visits/telephone calls
Contact with facilitators should be flexible and determined by patient characteristics and need	<ul style="list-style-type: none"> • Increase the number of contacts after a “trigger” event (e.g. hospitalization) • Delivered in-home or over the telephone • Individuals with higher need or limited social support would have more frequent contact
Select patients for participation in PHPI based on patient characteristics and need	<ul style="list-style-type: none"> • Characteristics: <ul style="list-style-type: none"> – More multimorbidity/higher mortality risk – Recent illness – Limited social support/financial support
Clarify the aims, process, and expectations of the PHPI	<ul style="list-style-type: none"> • Differentiate facilitator visits from in-home annual exam or wellness check • Clearly cover process of PHPI and priorities identification • Discuss timeline of visits/expected outcomes
Follow-up	<ul style="list-style-type: none"> • Schedule follow-up appointment with clinician within 1–2 weeks of facilitation
Reminders	<ul style="list-style-type: none"> • Include written take-home notes, that lists patient-identified health priorities • Encourage patients to take reminders to their follow-up clinician visit
Limit the number of forms patients are required to complete as part of the PHPI	<ul style="list-style-type: none"> • More face-to-face contact • Have research team collect patient health data when feasible
Involve family members throughout the PHPI process	<ul style="list-style-type: none"> • Encourage family participation during facilitation visit • Encourage family to accompany the patient to clinician visit
Facilitators should perform health-related clinical tasks in addition to identification of health priorities	<ul style="list-style-type: none"> • Discuss patient medications, medical conditions, and make recommendations regarding healthcare